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Ethical Challenges of Maternal-Fetal Medicine Practice in the United States

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Maternal-Fetal Medicine (MFM) is a subspecialty of Obstetrics and Gynecology that deals with various obstetrical, medical, and surgical complications of pregnancy. Care is provided for both the mother and fetus in a complicated pregnancy. The MFM specialist also provides education and research concerning the most recent approaches to the diagnosis and treatment of obstetrical problems. This promotes societal awareness of the diagnostic and therapeutic techniques available for the optimal management of complicated pregnancies. Less than 4% of obstetricians subspecialize in MFM. The type of practice varies. In addition to caring for women with high risk pregnancies in regional high risk centers, MFM specialists serve as consultants to the midwives, family practitioners, and obstetricians who provide the majority of pregnancy care in the U.S.

The sequence of the name Maternal-Fetal Medicine is deliberate. Mothers are essential and the loss of a mother is a devastating tragedy. Maternal mortality is the death of a woman while pregnant or within 42 days after delivery. The leading causes of death are blood loss, hypertensive disease, blood clots in major vessels, infection, and anesthetic accidents. Reliable records on maternal deaths have only been available since the mid-19th century. High maternal death rates were the rule until the 1930s when they began a rapid decline. One hundred years ago the chance of dying from pregnancy related causes was 1 in 200. Currently the risk is closer to 1 in 10,000 in the developed world. The persistent high risk of maternal death in the developing world is a glaring inequity, In places like sub-Saharan Africa it is nearly the same as it was a century ago. Most of the 500,000 mothers lost each year in the developing world could be saved by the provision of basic obstetric care.

This is because the major determinant of maternal mortality is the overall standard of obstetrical care provided to the patient. Poverty rates and nutrition have very little independent effect. During the 19th century the upper classes were at higher risk for maternal death because they were more likely to be attended by physicians who sometimes used dangerous interventions. (This historical fact should make those of us in medicine humble and should motivate us to be vigilant for similar dangers in modern medical practices.) Even in developed countries, maternal mortality is often preventable. Yearly surveillance of the rates on local, regional, national, and international levels provides information that can be used to prevent deaths in the future. A recent study of maternal mortality in Japan demonstrated what has been shown true elsewhere, that there is more danger when the same physician provides anesthetic and delivery care.

As one of ten high risk pregnancy specialists in a busy practice I see a complicated referral population. The subspecialty of MFM is only two and one half decades old and is unique in that we care for two patients in the mother and her unborn child. Sometimes our colleagues involved in the treatment of infertility are so successful that we have even more than two patients. As outlined by others at this conference, this is a situation which presents its own array of ethical dilemmas. Only on very rare occasions are the true medical interests of the mother and unborn baby in conflict.

Progress in the area of obstetrics and maternal-fetal medicine has been astonishing. By the middle of the 20th century obstetrics had made great strides in making pregnancy and birth a relatively safe experience for women. Developments in antibiotics, transfusion and anesthesia decreased the risk of maternal death

by 50-100 fold. Attention was then turned to improving the outcome for the baby-our second patient. Fetal monitoring was developed and some cases of fetal distress could be identified before and during labor. This was generally beneficial but also led to many unnecessary cesarean sections, not the first or last time that the best of intentions has had negative consequences.

During the late 1960's and early 1970's the development and use of Rh immune globulin decreased the number of pregnancies complicated by Rh problems. In those pregnancies where Rh incompatibility was present, fetal treatment was first used. This was accomplished by prenatal transfusion of blood into the abdominal cavity of affected fetal humans. The new focus on the baby was achieved by development of fetal ultrasound imaging technology. Prior to obstetrical ultrasound the anatomic development and activities of the fetus were invisible.

The developer of prenatal ultrasound, Professor Ian Donald of Scotland, served in the British Navy during World War II and became familiar with the use of sonar to detect submarines. By the 1960's he had developed exciting but unrefined methods of using sound waves to look into the uterus. During the 1970's and 80's the beneficial uses of ultrasound in pregnancy multiplied as the technology was improved. Today the practice of modern obstetrics would be impossible without ultrasound and nearly everyone has seen ultrasound images of babies before birth.

Current ultrasound imaging techniques reveal the marvelous complexity of prenatal growth and development. Just as parents of newborns mark their baby's developmental progress with activity milestones, thanks to ultrasound technology we can see similar developmental milestones for unborn babies. However the use of this wonderful window on the womb has become increasingly disconcerting for those who are willing to accord fetal humans only tentative and conditional protection.

Internet access to the National Library of Medicine by way of the Grateful Med program is one of the benefits of practicing medicine in the 21st Century. It is important to mention the times when government programs are an unqualified success. In only minutes one can do a comprehensive search of any combination of medical topics referencing thousands of medical journals published during the last thirty years. It is instructive to do a literature search covering the topic of treatment of babies before birth.

In the last two and one half decades three factors, rapid developments in genetics, ultrasound technology, and the increasing availability of fetal treatment options have expanded the concept of the fetus as a patient. Over that time the number of studies describing the fetus as a patient has multiplied. Between 1966-74 there were none, from 1975-1979 there were a few dozen, between 1980-1984 there were a couple of hundred. Over the last 16 years there have been thousands of articles describing the various ways that prenatal diseases can be detected and, increasingly, treated. There are also now numerous texts specifically addressing the fetus as a patient.

Fetuses can be treated with medications for dangerously irregular heart rhythms and heart failure. They can receive red blood cell or platelet transfusions if they are anemic or lacking in platelets. On rare occasions surgical procedures can be performed before birth. A frequent use of ultrasound is to evaluate the health of our unborn patients. In high risk situations we recommend frequent ultrasound "checkups" that look for prenatal breathing movements, other motor activities, and resistance to blood flow in the placenta. Normal findings on these tests suggest that the risk of stillbirth is low.

Fetal treatment centers have done basic and applied research on fetal medical and surgical treatment. One of the most dangerous abnormalities of fetal development in identical twins is the twin-twin transfusion syndrome. In this situation a vascular connection in the placenta allows transfer of blood leaving one twin anemic and the other overloaded. This problem can be diagnosed by prenatal ultrasound and pioneering groups perform in utero laser treatments to interrupt the interconnections. This has improved the outcome for some affected babies. Promising, though controversial, recent work has also been done with in-utero repair of neural tube defects such as spina bifida. These pioneers in prenatal surgery have found that fetal skin wounds heal without significant scarring. We are clearly in a new era of obstetrics because of ultrasound and the expanding concept of the treatment of the fetus as a patient. But the tragedy is that modern medicine works within a legal environment which says that a fetus is a patient only when the mother has conferred this status. The trouble is that this status can be withheld or withdrawn.

Another major component of MFM practice is prenatal diagnosis. This is the use of screening and subsequent targeted techniques to assess the anatomy and genetic makeup of the fetus. These range from maternal serum tests for various biochemical substances that can identify women at increased risk for fetal abnormalities, through detailed ultrasound studies, to invasive techniques that directly sample fetal cells.

Its use in the U.S. has expanded dramatically, although some commentators suggest that modern obstetrics is becoming an impersonal technospecialty dedicated to delivering "the perfect baby". Prenatal diagnosis can benefit the mother and baby when treatment options are available, but much of prenatal diagnosis is designed to detect fetal abnormalities so that the choice of abortion is available. But what fits the definition of an abnormality? Even abortion supporters are horrified by the possibility of abortions based only on the sex of the unborn child. But is abortion for the most sexist of reasons any worse than abortion for any other reason?

Despite claims that the abortion question has been settled, the ongoing debate over the morality of abortion complicates the practice of MFM. The premise of an unrestricted right to abortion dictates that a fetus is only conditionally a patient. Pending further developments in fetal treatment the major management option after prenatal diagnosis is what has been inaccurately termed "therapeutic abortion". The abnormalities which are "treated" by abortion range from lethal defects such as anencephaly, through often nonlethal defects such as trisomy 21, to correctable defects such as cleft lip and palate. At present between 50 and 80 percent of women carrying fetuses with various abnormalities are choosing abortion. It is debatable whether these decisions are made with truly informed consent.

Interdisciplinary studies are a benefit of participation in a University. The insights and expertise of specialists in areas other than my own gives a fresh perspective to my daily practice activities. Without new insights it is easy to grind on with the routine, missing the chance to improve my abilities so that I can better meet the needs of my patients. When following the trends in medical literature one can be taken by surprise. The application of cost/benefit analyses to prenatal diagnosis was an eye-opener for me. An important but disturbing article was published in the April 2000 issue of the American Journal of Medical Genetics. It uses estimated lifetime costs of various prenatally diagnosable problems to argue against any restriction of abortion following prenatal diagnosis. A copy of the article is available. I commend it to you for your reading and analysis.

Based on the current practice of MFM we are certainly offering and encouraging individual and family-based eugenics. Though we do not yet have an overt eugenic social policy there are an increasing number of articles using cost/benefit analyses to defend unrestricted abortion or to promote and encourage prenatal diagnosis (with abortion as the implicit "treatment option"). When argued for on this basis might we expect that individual pregnant women could eventually be pressured to submit to prenatal diagnosis for the social and fiscal health of society? Has the society become the patient on the basis of economic calculations?

The most frequently articulated defense of a right to abortion has been made on the basis of autonomy. This means that the decision to end or continue a pregnancy, whether or not the fetus is affected by an abnormality, is based on an individual decision by a woman using her own assessment of her situation, in consultation with her physician. The patient/physician relationship has also always been a personal one. But is that changing? Traditionally the primary role of the physician has been that of healer and counselor to the individual patient. There are obviously times when public health considerations are important, yet the duty to the individual patient takes precedence. There is great danger when physicians become agents for the state or when individual physicians subordinate their patient's best interest to what the physician believes are the best interests of society. I believe that we are currently on treacherous footing in this regard. Should cost/benefit analyses be applied to prenatal diagnosis when the most frequent intervention is abortion of the fetus?

Besides the starkly sinister effect of depriving preborn humans of life based on their anatomy or physiology there is another reason to oppose this practice. Making financial arguments for prenatal diagnosis/abortion ignores the unquantifiable commodity of human potential. Disability is a relative term and there is little correlation between the presence of a problem and what individual human beings can accomplish. According to what has been called "the disability rights critique" raised by advocates for the disabled, prenatal diagnosis of congenital anomalies followed by abortion is based on inaccurate information regarding living with disabilities. It is also claimed that this will weaken society's commitment to the inclusion and care of the disabled in our human community. A special supplement to the Hastings Center Report (Sept-Oct 1999) is an excellent summary of this critique.

As the human genome is laid open like a book we will all likely find genetic time bombs ticking away in our chromosomes - perhaps the near certainty of Alzheimer's Disease or a strong likelihood of cancer. To the degree that this information is used to develop prevention or treatment strategies it will be a benefit, but to the degree that it is used like current prenatal diagnosis it will be a threat to human freedom and potential.

In medical school, physicians are taught that signs of serious illness in our patients are often subtle. On a larger scale, the beginning of an epidemic can be detected by identification of a small number of early cases. These principles of good medical practice should be applicable to signs of a dangerous moral pathology, even when the disease arises within the medical profession itself. Will doctors be alarmed by the application of cost/benefit analyses in these ways? We shall see. In the crucial area of moral judgment, modern medical education can anesthetize its students. Hopefully the level of moral anesthesia induced is not too deep or widespread.

The disabled community suggests that the rest of society should be known as the "temporarily abled". This is because disability can be acquired as well as inherited. It can be in your genes or it can come in the aftermath of an automobile accident. It can affect any one of us. Therefore we should be vigilant for trends such as this that place a value on persons by calculating what they will cost society. That is a path that was trod only too recently and it darkened the middle of the last century. We should have the wisdom and moral courage to refuse to go that direction again.

In the United States we are dealing with the medical, social, and political fallout of our Supreme Court's willingness to erase the traditional boundaries of medical ethics and practice. The tenets of Hippocratic medicine have served us well for more than 2,000 years. Our 27 year experiment with unrestricted abortion has caused the practice of medicine to become increasingly inconsistent. The tension between valuable protective ethical traditions and currently legal medical practice is untenable. Using cost/benefit analyses to argue for prenatal diagnosis and abortion cannot factor in the loss of individual human potential nor can it avoid the erosive effect that abortion for traits or characteristics will have on society's commitment to the disabled. The outlook for MFM practice in the future should resemble a promising sunrise, but there are some very ominous clouds forming on the horizon.